Request for NIH One Percent Set-Aside Funding for

Evaluation of the National Cancer Institute's Cancer Information Service

National Institutes of Health
National Cancer Institute
Office of Communications
Office of Cancer Information Service

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Section 1 – Program to be Evaluated

1.2 Program to be Evaluated

Since its founding in 1976, the Cancer Information Service (CIS) has been the voice of the National Cancer Institute (NCI). CIS provides cancer information and education to cancer patients, their friends and families, the general public, and health professionals through a network of 14 regional contracts; it serves all 50 States, Puerto Rico, the U.S. Virgin Islands, and U.S. Territories. CIS comprises three programs; each is briefly described below:

- **The Information Service** provides recorded cancer information, NCI publications, and personalized cancer information in English and Spanish, offered by trained Cancer Information Specialists, through a toll-free number (1-800-4-CANCER). Users also can access information on smoking cessation (1-877-44U-QUIT). The CIS responds to cancer inquires via *LiveHelp*, a Web-based instant messaging service, and a TTY line for the deaf and hard of hearing.

- **The Partnership Program** collaborates with organizations regionally and nationally to reach minority and medically underserved populations, as well as populations with limited access to health and cancer information.

- **The Research Initiative** collaborates with researchers to conduct cancer communication research. The primary goal of this initiative is to foster research that can strengthen CIS' cancer communication activities, as well as the cancer communication efforts of other organizations.

The FY 2004 CIS budget, including regional contracts (located at cancer centers across the country), is just over $28 million. The total number of program staff in the CIS network is 368.

Evaluation of the CIS Information Service through a National Users Survey will assess satisfaction and the effect of the service on users of the CIS 800 numbers and its *LiveHelp* service. The evaluation consists of three phases: Phase I consists of the design and development of the National Users Survey instrument; Phase II includes the implementation of the instrument; and Phase III consists of data analysis and reporting of the results of the evaluation. The purpose of this application is to seek funding for Phase III.

This evaluation is one aspect of a CIS Comprehensive Evaluation Plan, which includes evaluations of the Partnership Program and Research Initiative. A National Partner's Survey (N=288) was recently completed (July 2003). Ninety eight percent of partners said they were satisfied with CIS and ninety six percent felt that their work with the CIS had an impact on the populations they serve.

1.3 Program Goals

CIS program objectives relevant to this evaluation are:

1. Provide access to and disseminate the latest and most accurate cancer information to the public.

2. Tailor cancer information and education in response to the needs and expectations of the audience.

3. Increase awareness of the programs, products, and services of the NCI.

4. Increase the public's knowledge about cancer and encourage positive attitudes, self-efficacy,[*] and behavioral changes related to cancer.

Section 2 – Need for an Evaluation

2.1 Type of Evaluation

Evaluation of the CIS Information Service provides both process and outcome (short and long-term) measures. The process evaluation assesses the extent to which CIS programs have been implemented as intended and how satisfied users were with the service. For example, the process evaluation provides CIS with information about the public's access to information and services and cancer information dissemination. The outcome evaluation assesses both the short-term and long-term effects of the program and what has changed as a result of the program. Among the public, short-term effects include changes in knowledge, attitudes, and self-efficacy. Long-term effects are changes in cancer-related behavioral intention and behavior (e.g., prevention and screening behaviors; empowered decision making related to treatment and quality-of-life issues).

2.2 Purpose of the Evaluation

Evaluation of the CIS Information Service will enhance NCI's understanding of the accessibility of the service to underserved populations, quality of the service and products, user satisfaction, and how NCI information and materials are disseminated. The evaluation also will determine the effect on users' knowledge, attitudes, self-efficacy, and behavioral intentions and behaviors related to cancer. Findings will add to the knowledge gained during previous Users Surveys (1984, 1996) and pave the way for another survey planned during the next CIS contract cycle (2004-2006).

[*] That is, an individual's sense that she or he is competent to deal with important life situations from an informed position of strength and motivation.

2.3 Use of Results

Increasing public awareness and knowledge about cancer prevention, screening, treatment, clinical trials and tobacco is critical to the mission of the Department of Health and Human Services (DHHS), the National Institute's of Health (NIH), and the National Cancer Institute (NCI). The National User Survey will focus on how the information provided by the CIS is used by the public and help NCI know how best to meet the informational needs of users. (Please also see section 2.2; purpose and results are to some extent inextricably bound together.)

All NIH institutes are charged with providing information to the public at large. Many have information clearinghouses; some offer limited information over the telephone (usually at toll-free numbers); all have Web sites. Many of these services have been evaluated to determine user satisfaction and ways that the service might be improved to be more efficient, responsive, user friendly, etc. However, as far as we could tell, there have not been evaluation efforts to determine whether the information provided actually sparked behavior change or affected a user's intention to change (or fortified the user's sense that change was possible—i.e., improved a user's perception of self-efficacy). Yet much of the information distributed by many institutes is aimed, implicitly or explicitly, at doing just that: encouraging people to engage in preventive behaviors (e.g., lose weight, exercise, quit smoking); supporting decisions to seek treatment for both physical and emotional problems; informing people about the possible risks and benefits of complementary and alternative medicines/practices with the hope of motivating them to thoroughly explore these topics with a health care professional; fostering parenting skills by broadening the understanding of child development. Nearly every institute where it is appropriate has a mechanism for informing people about clinical trials and how to enroll, and most provide referrals to other agencies and organizations that can either supplement information or provide more direct service. The NCI Clinical Studies Support Center (1-888-NCI-1937) reported that talking with patients does, at least anecdotally, seem to increase their interest in and willingness to join a study. In sum, changing the public's behavior with regard to a particular health concern is an underlying theme for much of the work done at NIH.

The National Users Survey will provide a first glimpse into whether the kind of information services provided at NIH *does* motivate additional behavior. We are asking participants' about their "before-and-after" knowledge of cancer.[*] The literature is clear on the need for knowledge as a foundation for behavior change and movement to the next "stage of change."*[*]

We believe that what we learn from this survey will be valuable to sustaining and increasing other institutes' public information services, and that some techniques used by the CIS can be adopted elsewhere in NIH. As members of the NIH Education/Health Communication Network, comprised of 9 institutes, CIS will share User Survey results and initiate collaboration with institutes who may want to apply tested measures of mutual interest to their own surveys. In

[*] Survey participants will be drawn from people who had contacted the CIS for the first but only time before the survey began (see section on sampling procedures).

[*]*This behavior change model posits that people pass through several stages before actually changing a behavior, and that this passage tends to be fairly uniform and predictable.

addition, CIS is a member of the Health Information National Trends Survey (HINTS) working group for the 2005 administration of this nationally representative survey of the general public. HINTS is designed to fill the gap in knowledge about access, sources, and trust of cancer-related information or factors that facilitate or hinder health communication on a population-wide basis. CIS data will be used to augment items on HINTS that relate to CIS, knowledge, attitudes, beliefs, and behaviors concerning cancer and cancer-risk factors

2.4 Review of the Literature

The Cancer Information Service (CIS) has a rich history of evaluation research that uses both a unified data source and uniform data-collection instruments. The first concerted efforts at developing an evaluation plan for the network began in late 1975 with the creation of an evaluation task force (Morra et al., 1993B). A 1976 a telephone users' satisfaction survey, the only one lacking uniform data and methodologies, spawned a network-wide adoption of a standardized Call Record Form and inauguration of the CIS test call system in 1980. Standardized operations have been the rule since 1982. A 1984 national user survey assessed the information needs and the effectiveness of CIS in affecting health behavior as compared with other sources, and the extent to which CIS influenced users' health behavior (Morra et al., 1993A). Results of the survey showed high user satisfaction and the importance of CIS in helping users make decisions to take a health-related action (Freimuth, Stein, and Kean, 1989).

CIS research and evaluation efforts have continued and now comprise an important part of the literature on assessing the quality, effects, and effectiveness of information services. Among other important outcomes, results from a 1996 Users Survey have shown that the information users received has a beneficial impact in terms of eliciting a positive action or providing reassurance for decisions (Ward et al., 1998) and that the CIS plays an important role in empowering users to make health-related decisions regarding clinical trials (Davis et al., 1998) and cancer prevention and screening (Maibach et al., 1998).

See ***Appendix A*** for complete references and bibliography.

2.5 Timeliness of the Evaluation

Congress enacted the Government Performance and Results Act of 1993 to focus on improving program performance and providing greater accountability for results in the Federal Government. The CIS evaluation plan is designed to satisfy this mandate and yields feedback for results oriented management of the service.

Results of the Users Survey will help NCI manage the CIS and provide the best value not only to the users but to the Federal Government as well.

In addition, the 14 CIS contracts are up for re-competition; a final solicitation was posted (November 26, 2003) and new contracts will be awarded in October 2004. Results from the National Users Survey will supplement information about incumbent offeror's past performance, regional quality, and other performance data collected over the current contract period.

Section 3 – Evaluation Design

3.1 Study Questions

The National User Survey focuses primarily on the short-term effects (and prospects of longer term effects) of the CIS on users. The following study questions guide the survey:

- **Knowledge.** Does use of the Information Service increase users': (1) knowledge and awareness about cancer topics, (2) communication with health professionals, and (3) ability to acquire information about the subject of their inquiry?

- **Self-Efficacy.** Does the use of the Information Service increase users' self-efficacy with regard to communicating with health professionals about cancer, personal health promotion, and cancer-related decision-making?

- **Behavioral Intention and Behavior.** Does use of the Information Service increase users' intentions and behaviors related to positive health promotion and treatment behaviors, and their communication with health professionals?

- **Satisfaction.** Are the CIS users satisfied with the service and the information they receive?

3.2 Target Population

The sampling frame for the survey will include all telephone and *LiveHelp* users from whom CIS has requested demographic information; that is, 50% of patients, family/friends, and general public. Collection of these data is approved as part of usual service (OMB 0925-0208 expires 11/30/06). Rationale for the collection of 50% on user demographics is based on the regional configuration of the CIS. Collecting less than 50% of these data compromises our ability to carry out specific program evaluation at the smaller geographical level. Generally, the 50% collection on demographic questions provides enough data to support program planning at the national and regional level, as well as collaborations between partners and researchers. Fifty percent collection on special promotions allows NCI to track the success of cancer messages and also provides enough data for the CIS regions to use within their cancer center institutions and in collaboration with other organizations, such as State health agencies.

3.3 Key Variables

Population Characteristics: In general, typical CIS users are white (86%), educated (29% some college) women (70%) in the 50-59 age range. The survey sampling frame consists of all first time consenting users who contacted CIS just before or during the field period and whose contact was flagged for collection of demographic data. Within each stratum, users are ordered by their state of residence and within gender to ensure adequate representation of these characteristics. A systematic sample is being taken within each stratum. Cases for which all, some, or none of the demographic data were provided by users will be sampled. To better meet the needs of the

underserved public, we are placing emphasis on a subgroup of users. The subgroups of particular interest, and those of which NCI is especially interested in obtaining reliable estimates, include: patients, people who contacted CIS about smoking or other forms of tobacco use, and minorities. After considering the proportion of the user population in each of these subgroups, users who contacted CIS about smoking or other forms of tobacco are sampled by a factor of three. All other cases, including patients and minorities, are sampled at a rate that will result in a total of 2,500 completed interviews. It was determined that sufficient reliability for patients and for minorities was achievable without over sampling from the other subgroups.

Sample Size: Twelve equal samples will be selected on a weekly basis. Each of the 12 samples provides about 208 completed interviews (2,500 interviews in all). At a 75 % response rate, calls are made to about 278 persons in each of the samples. Sample size is being adjusted for lower or higher response rates.

Program Activities: The telephone and *LiveHelp* service activities are the primary activities that will be evaluated. Of note, is an assessment of the effect of the service on smokers wishing to quit (a group that is over sampled). These data will yield useful information about the possible effects of contact on behavior and whether users changed or found change easier to contemplate as a result of their contact. Survey results will provide a baseline for implementing an evidence-based, proactive, call-back service for smokers in the new CIS contracts.

Program goals, performance measures, and comparison measures: As performance and comparison measures, we will use the most recent user survey conducted by the CIS in 1996 as the baseline variable on some measures in the current survey. We seek to match or exceed the percent of respondents answering affirmatively on the following variables (as listed by Ward et al. [1998]):

- **Satisfaction:** 95.2% answered "very satisfied" or "somewhat satisfied."
- **Knowledge:** 92.3% answered affirmatively to increased knowledge question
- **Self-Efficacy:**
  - ✓ **Helpful in decision-making:** 66.8% answered affirmatively
  - ✓ **Information aided coping:** 73.7% answered affirmatively
- **Behavior and Behavioral Intent:**
  - ✓ **Positive health actions reported:** 56.4% answered affirmatively
  - ✓ **Discussed with health professional**: 45% answered affirmatively

External Factors: Although positive change in knowledge, attitude, and behavior (KAB) related to cancer-related issues is an appropriate goal of the Cancer Information Service (CIS), the ability to measure such changes through the User Survey is limited by several design features:

- *Measurement at a single point-in-time*. Since the study design asks users to participate in a single interview, we must rely on participations to provide retrospective reports of KAB change and their attribution of change to their contact with CIS. We feel confident in users' ability to perform these tasks when asked questions specifically related to their reasons for contact. For example, we believe that users who contacted CIS for information on tobacco cessation can describe changes in their attitudes or behaviors related to tobacco use and to attribute those changes to information received from CIS. This will allow us to compare changes in the proportion of callers who attributed changes in KAB related to their reason for contact to CIS during the 2003 survey cycle to proportion from the 2006 survey. This information, in turn, will allow NCI to measure and evaluate the effects of changes in the CIS made during that time.

- *Time period between contact with CIS and survey administration*. The current study design calls for interviews to be conducted between 2 and 3 weeks from contact with CIS. The original evaluation design called for survey administration between 4 and 6 weeks after contact with CIS, thereby allowing relatively more time for changes in KAB to take hold. However, we recognized that this time span would diminish users' ability to accurately recall aspects of the interaction with CIS. While the shortened time span increases recall, it lowers the likelihood that changes will have occurred.

- *Length of interview*. Efforts to minimize respondent burden and the constraints of survey resources contributed to the decision to prepare a 10-minute interview. Given the broad array of topics to be addressed in the survey, the overall time limit prevents the collection of in-depth information about any single topic. An example of how this affects the ability to measure change is the effect on questions related to behavior change. The survey could ask: *What specific steps do you believe you can take to reduce the chance of getting cancer – such as changing your diet?* However, several follow-up questions would have to be added to properly assess attitude change related to each behavior. For example, we would need to determine if users who respond negatively do so because they already engage in healthful eating behaviors. In addition, to measure change as specified in the model, we would have to determine whether this attitude was affected by the contact with CIS. To do this, we would have to ask those who answered affirmatively how their attitude was influenced by their contact.

3.4 Conceptual Framework

See ***Appendix B***: Information Service Logic Model

Section 4 – Data Collection

4.1 Data Sources

Archival Data: The 1996 Users Survey will serve as a source of archival data and as a baseline against which to measure certain data items (see above, Section 3.3) such as satisfaction, knowledge, self-efficacy (in decision-making), behavioral intent and positive health actions reported (discussed with health professional**).**

New Data: A survey instrument (See ***Appendix C:*** National Users Survey) has been developed in collaboration with the NCI Project Office, a CIS Evaluation Advisory Committee, and Westat, a social science research firm in Rockville, Maryland. The survey was pre-tested before implementation (see details below Section 4.3).

Data Collection Strategies**:** As part of usual service, data are collected on all contacts to the CIS. Information Specialists, use a web based electronic contact record form (ECRF) to collect data on variables including; type of user, subject of interaction, primary cancer site, actions taken, customer service questions and user demographics (50%). For the survey, at the end of usual service, Information Specialists recruit all (except distressed) users flagged for demographic collection. Information Specialists obtain informed consent and request contact information from the user. These data are entered into a recruitment screen appended to ECRF. Weekly ECRF files are exported to Westat for uploading into their CATI (computer-assisted telephone interviewing) system. Trained interviewers call respondents within 30 days of the initial contact and administer the 10-minute interview using the CATI system. The survey is being conducted for 14 weeks (November 3 to December 21, 2003 and from January 12 - February 29, 2004). Twelve equal samples are selected on a weekly basis. Each of the 12 samples is planned to provide about 208 completed interviews (2,500 interviews in all). We anticipated about a 75 percent response rate, which will require us to call about 278 persons in each of the samples. We have completed 239 interviews thus far (11/24/03) with a 95% response rate. We will continue to observe progress and adjust the sample size for later samples accordingly.

4.3 New Data Collection Instruments

Primary purpose of the instrument: The National User Survey includes core questions that apply to all types of CIS users, as well as specific questions pertaining to the main reason the user contacted the service is being administered. Domains assessed include: user satisfaction with the service and information they were provided; increased user knowledge with regard to awareness of cancer topics, communicating with health professionals, and acquiring information about topic of call; increased user self-efficacy with regard to communicating with a doctor or other health professional, personal health promotion, and cancer-related decision making; increased user intention to pursue treatment options or clinical trials; and, increased user behavior related to pursuit of treatment options or clinical trials, communication with a doctor or other health professional, and cancer and tobacco use prevention and tobacco use. The survey

contains a total of 48 closed-ended questions. Each question corresponds to one of the aforementioned domains or is an item needed to correctly route respondents through the questionnaire to ensure that respondents are only asked questions relevant to the reason for their contact with CIS. For example, if a respondent contacted CIS for cancer information unrelated to smoking or other tobacco-related issues, they would not be routed to the section of tobacco-related questions. Likewise, if respondents were informed by a CIS Information Specialist about participating in clinical trials, but they were not interested in receiving this information, the respondent would not be asked the set of questions about clinical trials.

The process that was used to design and pretest the instrument: The National User Survey instrument was designed by Westat survey methodologists in close collaboration with the NCI Project Office. The CIS Evaluation Advisory Committee reviewed the instrument and provided feedback based on experience with CIS users. The draft instrument was pre-tested (July 28—August 7, 2003) with 9 respondents recruited by three CIS offices. Respondents were selected by access point (telephone or LiveHelp), type of user, and subject of interaction. The pre-test tested each branch of the survey, determined how long it took to complete, assessed respondents' comprehension of each question, and determined whether wording is clear. Pre-testing was conducted by telephone and simulated the actual method of survey administration. Respondents were asked about their understanding of and reactions to the survey questions. Based on their feedback, some survey items were revised and some were eliminated.

How the instrument is being administered: The National User Survey is being administered by trained survey interviewers at Westat. The survey is administered no more than 2 to 3 weeks after an individual contacts the CIS. The phone interviews begin with a screener to determine whether the eligible person lives in the household and whether s/he has used the CIS in the past 30 days. Upon completion of screening, the interview continues if the screener respondent is the eligible person. Callback appointments are made as necessary to reach respondents if they are not available and a letter detailing the survey and providing NCI and Westat contacts is offered if necessary (See ***Appendix D:*** Letter to Respondents).

Approximate number of questions: The core of the survey instrument contains 19 questions, with additional branching questions that total 48 items; completion time is 10 minutes.

Study questions to be addressed using the instrument: The table below shows the questions.

Knowledge: Does the use of the Information Service increase users'

- Knowledge about and awareness about cancer topics?
- Knowledge of communicating with health professionals?
- Knowledge of how to acquire information about the cancer-related subject about which they contacted CIS?

Satisfaction: Does the use of the Information Service

- Meet users' expectations for the quality and thoroughness of service?

Self-Efficacy: Does the use of the Information Service increase users' self-efficacy

- With regard to communicating with health professionals about cancer?
- With regard to personal health promotion (including smoking cessation)?
- With regard to cancer-related decision-making?

Intention: Does the use of the Information Service increase users'

- Intention to pursue treatment options, clinical trials, and services?

Behavior: Does the use of the Information Service increase users'

- Positive treatment behaviors (e.g., pursuit of treatment options, clinical trials, services?)
- Reported ability to communicate with health professionals?
- Healthful behaviors related to cancer prevention (including smoking cessation)?

4.4 Clearance Requirements

The CIS has received approval from the U.S. Office of Management and Budget to conduct the CIS Comprehensive Evaluation (OMB #0925-0500 expires 6/30/2005). Under the terms of the approval, the National User Survey instrument and a sampling plan were submitted in September and approved for administration in October, 2003.

4.5 Data Integrity

Data integrity involves the accuracy of the data represented in the computer and is addressed through error prevention and error detection. This is accomplished through a combination of data-processing procedures and computer programs designed to minimize the loss of data, identify data problems as soon as possible, and ensure that the data in the system represents the information on the form itself. Standard procedures and guidelines are in place to address the issue of error prevention; this includes such items as decision logs, which are used to record independent decisions made by data-preparation supervisors regarding situations that are not covered in the manual of operations, as well as checks for data logic and correct skip patterns.

Interviewers are trained and monitored to ensure quality and accuracy of administration. Westat interviewers completed training (11/15/03) that provided an overview of the CIS and a session to introduce them to the study and familiarize them with the questionnaire. Trainees reviewed an interviewer's manual, practiced answering commonly asked questions, learned appropriate refusal/avoidance techniques, and completed role-plays simulating interviews. All aspects of interviewer performance are being monitored by management and supervisory staff throughout the data-collection period. The NCI Project Officer is monitoring interviews on a select basis from a remote location. Interviewers are apprised of their strengths and areas needing improvement.

4.6 Ethical Considerations

During the OMB process, the ethical considerations necessary for proper data collection and analysis were defined. Specifically, the confidentiality of users is protected and assured to safeguard the security of the respondent. In addition, CIS Information Specialists are trained to

use their discretion in the recruitment phase. Distressed users are not recruited to the survey. The Electronic Contract Record Form has a Distressed User button that Information Specialists can click to indicate why a potentially eligible user was not recruited to the survey. These users are excluded from the sample.
Regarding data security, Westat is using standard procedures to back up data on a tape that is then stored in a secure location and a program has been written to delete confidential personal identifying information prior to backing up the data.

4.7 Data Preparation

Westat is conducting data collection, data receipt, editing, coding, keying, and data analysis; and has developed statistical reports for use when data collection is completed. Variation in responses among demographic groups will be explored, and the report will focus on determining the effects of the CIS on its users. Data will be analyzed to determine if the Information Service is more effective with some groups of users than others.

4.8 Data Analysis

Descriptive and inferential statistics are being used to analyze the data. Prior to sampling, Westat will sort each file by several variables. Such sorting results in implicit stratification and is beneficial in that it better insures that the achieved sampling rate will be the same for each category of a sort variable. The sort variables that were prioritized in rank order by NCI include user type (patient/non-patient), race/ethnicity (Hispanic/non-Hispanic), smoking cessation gender, and CIS region. The order in which the sorts are performed is important in that more control is achieved for the first few sort variables and less control will be achieved for the last few sort variables.

Base weights will be set equal to the inverse of the probability of selection. Westat will then do a post stratification or/and raking adjustment. Control totals for this adjustment will be sampling frame estimates by the demographic groups used for sorting. This will serve as a noninterview adjustment as well as account for any deviations between the sample and frame distributions. Estimates of standard errors will be computed using jackknife replication. Replication involves splitting the entire sample into a set of groups or replicates, based on the sample design of the survey. The survey estimates will then be computed for each of the replicates by creating replicate weights that mimic the actual sample design and estimation procedures used in the full sample. The variation in the estimates computed from the replicate weights will then be used to estimate the sampling errors of the estimates from the full sample. This computation will be done using WesVarPC, a Windows-based statistical software package used for analyzing data from complex surveys. WesVarPC computes the estimates and the replicate variance estimates that reflect the complex sampling and estimation procedures that will be used for this survey.

Section 5 – Evaluation Results

5.1 Products of the Evaluation

Westat will write a full report on the results of the National User Survey. This report will contain details about the survey methods, key findings, conclusions, and recommendations. In addition, the full report will present data using easily understandable tables and graphs. An executive summary will be developed to present the results of this evaluation to NIH, NCI, and other stakeholders.

5.2 Dissemination of Results

CIS Program Directors in each region will receive a final report on the outcomes of the National User Survey. Stakeholders, including NCI program planners, the NCI Office of Communications, and other interested parties will also receive a report on the results of the survey. Survey results will be showcased in appropriate forums for the CIS and formatted for distribution based on program need or requests.

In addition, other appropriate NIH institutes and centers will be provided copies. We will advise them of findings and potential collaborations through a specially tailored report on the findings, of results that have relevance to their work and objectives (see Section 2.3 above).

Section 6 – Project Management

6.1 Project Implementation

The NCI Project Office has contracted Matthews Media Group for evaluation support. As a subcontractor to Matthews Media Group, Westat, a nationally known, private research firm in Rockville, Maryland, is providing expertise and support in the implementation of National User Survey evaluation.

6.2 Advisory Committee

An Evaluation Advisory Committee comprised of CIS program leaders, NIH, NCI, and other academic officials reviewed the CIS Comprehensive Evaluation Plan and assisted in the development of the National User Survey instrument (See ***Appendix E***: Evaluation Advisory Committee). A copy of the summary report of the results of the evaluation will be made available to the Committee upon completion.

6.3 Estimated Timeline for the Evaluation

The Evaluation Plan is designed for the current contract period, ending October 14, 2004. The estimated timeline for evaluation is as follows:

- Phase I: Pre-administration (survey development, sampling) Jun 2003 → Oct 2003
- Phase II: Survey Administration Nov 2003 → Feb 2004
- Phase III: Post administration (data analysis and reporting) Apr 2004 → Jun 2004

Section 7 – Budget Estimate

7.1 Estimated Costs

The attached spreadsheet summarizes the costs of all three phases of the evaluation ($309,553). However, funds are only requested to cover the estimated expenses associated with Phase III ($100,000). NCI is covering all costs in excess of $100,000 ($209,553).

7.2 Anticipated Funding Sources

See attached spreadsheet

APPENDIX A: REFERENCES AND BIBLIOGRAPHY

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APPENDIX B: CIS INFORMATON SERVICE LOGIC MODEL

(see PowerPoint Slide attached to email)

Appendix C:

CIS USER SURVEY 2003
Oct 23, 2003

Hello, may I please speak with [NAME]?

My name is [NAME] and I am calling from Westat on behalf of the National Cancer Institute about an evaluation we are conducting for the Cancer Information Service. The Service includes the 1-800-4-CANCER number, the Quit Smoking Line, and the cancer.gov web site. [IF NEEDED: The Quit Smoking Line telephone number is 1-877-44-U-QUIT.]

The study we are conducting is for the National Cancer Institute. A few weeks ago, you agreed to share your thoughts about using the Cancer Information Service. I'd like to talk with you now about your experience with the Service. Your participation in this study is voluntary and will not in any way affect the information or service you receive from the Cancer Information Service. Everything you tell me will be confidential and you are free to end the interview at any time. If there are any questions you would prefer not to answer, we can skip them. The interview will take about 10 minutes.

Do you have any questions before I begin the interview?

First I'd like to ask about all cancer organizations that you may have contacted recently.

A1. Not counting times when you contacted the Cancer Information Service or the Quit Smoking Line, in the past 30 days, have you contacted **other** cancer organizations or websites to find information on a cancer-related topic?

YES	1 (GO TO QA2)
NO	2 (GO TO QA3)
REFUSED	-7 (GO TO QA3)
DON'T KNOW	-8 (GO TO QA3)

A2. What other organizations or web sites did you contact during the past 30 days? [CODE ALL THAT APPLY.]

ORGANIZATIONS

AMERICAN CANCER SOCIETY	1
AMERICAN LEGACY FOUNDATION	2
AMERICAN LUNG ASSOCIATION	3
CANCERCARE	4
NATIONAL ALLIANCE OF BREAST CANCER ORGANIZATIONS	5
NATIONAL COALITION FOR CANCER SURVIVORSHIP	6
SMOKE STOPPERS	7
STATE QUIT LINE	8
SUSAN G. KOMEN FOUNDATION	9
US TOO	10
WOMEN'S CANCER NETWORK	11
Y-ME NATIONAL BREAST CANCER ORGANIZATION	12

WEBSITES

MEDLINE PLUS	13
ONCOLINK	14
SMOKEFREE.GOV	15
WEBMD	16
OTHER (SPECIFY) _____	91
REFUSED	-7
DON'T KNOW	-8

[For the rest of this survey, I will only be asking about your experience with the Cancer Information Service, either online at the cancer.gov web site or by phone at either 1-800-4-CANCER or by calling the Quit Smoking Line at 1-877-44-U-QUIT.]

A3. During the past 30 days, did you access the cancer.gov web site?

YES	1 (GO TO QA3A)
NO	2 (GO TO QA5)
REFUSED	-7 (GO TO QA5)
DON'T KNOW	-8 (GO TO QA5)

A3A. How many times during the past 30 days have you accessed the cancer.gov web site? Would you say…

Once, or	1
More than once?	2
REFUSED	-7
DON'T KNOW	-8

A4. During the past 30 days, did you use the cancer.gov LiveHelp service to have an online conversation about cancer or cancer resources?

YES	1 (GO TO QA4A)
NO	2 (GO TO QA5)
REFUSED	-7 (GO TO QA5)
DON'T KNOW	-8 (GO TO QA5)

A4A. How many times during the past 30 days did you use the cancer.gov LiveHelp? Would you say…

Once, or	1
More than once?	2
REFUSED	-7
DON'T KNOW	-8

A5. During the past 30 days, did you contact the Service using either their 1-800-4-CANCER telephone number or by calling the Quit Smoking Line at 1-877-44-U-QUIT?

YES	1 (GO TO QA5A)
NO	2 (GO TO BOX AFTER QA5A)
REFUSED	-7 (GO TO BOX AFTER QA5A)
DON'T KNOW	-8 (GO TO BOX AFTER QA5A)

A5A. How many times during the past 30 days did you contact the Service by telephone? Would you say…

Once, or	1
More than once?	2
REFUSED	-7
DON'T KNOW	-8

If QA3=2, -7, or -8 and QA5=1, go to Q6 (contacted by telephone only).

If QA5=1 and QA3=1 and QA4=3, -7, or -8, go to INTRO1A (contacted by telephone and cancer.gov website, did not use LiveHelp).

If QA5=2, -7, or -8 and QA3=1 and QA4=1, read INTROB (did not contact by telephone, used cancer.gov website and used LiveHelp).

If QA5=1, and QA3=1, and QA4=1, read INTROC (contacted by telephone, used cancer.gov website and used LiveHelp).

If QA5=2, -7, or -8 and QA3=2, -7, or -8, go to CLOSE1.

If QA5=2, -7, or -8 and QA3=1 and QA4=2, -7, or -8, go to CLOSE1.

(CLOSE 1-Thank you very much for your time but we are only conducting this survey with people who have contacted the Cancer Information Service by phone or through their LiveHelp service online.)

INTRO1A: For the rest of the survey, please think only about your experience(s) using the telephone service.

INTRO1B: For the rest of the survey, please think only about your experience(s) using the LiveHelp service to have an online conversation about cancer or cancer resources.

INTRO1C: For the rest of the survey, please think only about your experiences using the telephone service a-nd the LiveHelp service to have an online conversation about cancer or cancer resources.

B1. *+Did you contact the Service to get information mainly for…

[IF FOR MULTIPLE PEOPLE, PROBE: Who would you say you were mainly calling for?]

[IF R STILL HAS DIFFICULTY CHOOSING, PROBE: For the purpose of this survey, please answer for only one person you are calling about.]

yourself, ...	1	(GO TO QB3)
a family member, or.....	2	(GO TO QB2)
a friend?	3	(GO TO QB3)
REFUSED.....	-7	(GO TO QC1)
DON'T KNOW	-8	(GO TO QC1)

B2. How is this family member related to you? [IF R HAS DIFFICULTY CHOOSING: For the purpose of this survey, please answer for only one person you were calling about.]

HUSBAND.....	1
WIFE.....	2
PARTNER	3
FATHER.....	4
FATHER IN LAW	5
STEPFATHER	6
MOTHER	7
MOTHER IN LAW.....	8
STEPMOTHER.....	9

SON	10
STEPSON	11
DAUGHTER	12
STEPDAUGHTER	13
BROTHER	14
BROTHER IN LAW	15
STEPBROTHER	16
SISTER	17
SISTER IN LAW	18
STEPSISTER	19
UNCLE	20
AUNT	21
GRANDFATHER	22
GRANDMOTHER	23
OTHER (SPECIFY) _____	91
REFUSED	-7
DON'T KNOW	-8

B3. (Have you/has your [RELATION/friend]) been diagnosed with cancer?

YES	1	(GO TO QB4)
NO	2	(GO TO QC1)
REFUSED	-7	(GO TO QC1)
DON'T KNOW	-8	(GO TO QC1)

B4. (Are you/is your [RELATION/friend]) currently receiving treatment for cancer?

YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

C1. People contact the Service for different reasons. I am going to read a list of some common reasons and please tell me if any of the following were reasons you contacted the Service.

Did you want information about tobacco or ways to quit or cut back on smoking or using other kinds of tobacco, such as chew, spit, or snuff?

YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

If QC1=1(respondent wanted tobacco information), ask QC1A.

C1A. Were you specifically seeking information about…

	YES	NO	REF	DK
a. ways to quit or cut back on smoking?	1	2	-7	-8
b. ways to quit or cut back on using other kinds of tobacco, such as chew, spit, or snuff?	1	2	-7	-8
c. other information about tobacco?	1	2	-7	-8

C2. Did you want information to help you talk with a doctor or other health professional? [FOR EXAMPLE, ONCOLOGIST, SURGEON, RADIATION THERAPIST, NURSE, MEDICAL TECHNICIAN, SOCIAL WORKER, ETC.]

YES 1
NO 2
REFUSED ..... -7
DON'T KNOW ..... -8

C3. [When you contacted the Service] Did you want to talk about or confirm information you received from a doctor or health professional?

YES 1
NO 2
REFUSED ..... -7
DON'T KNOW ..... -8

C4. [When you contacted the Service] Did you want information about clinical trials such as screening, prevention, treatment, or other types of trials?

YES 1
NO 2
REFUSED ..... -7
DON'T KNOW ..... -8

C5. Did you contact the Service for any other reason?

YES 1
NO 2
REFUSED ..... -7
DON'T KNOW ..... -8

C5A. What was that reason?

_____

If QC4=1 (respondent called for information about clinical trials) go to D1. Else, go to QC6.

C6. When you contacted the Service, did you receive information about cancer clinical trials such as screening, prevention, treatment, or other types of clinical trials?

YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

D1. Now I'd like to talk with you about your overall experience with the Service.

Think about what you expected or hoped to get from your contact with the Cancer Information Service. Overall, were your expectations…

Met,	1
Exceeded, or	2
Not met?	3
REFUSED	-7
DON'T KNOW	-8

D2. In general, would you say the (person/people) you worked with (was/were)…

Very knowledgeable,	1
Knowledgeable,	2
Somewhat knowledgeable, or	3
Not at all knowledgeable?	4
REFUSED	-7
DON'T KNOW	-8

D3. At this time, how much do you feel you can trust the information that you received? Do you feel you can trust the information…

A lot,	1
Somewhat,	2
A little, or	3
Not at all?	4
REFUSED	-7
DON'T KNOW	-8

D4. Overall, how satisfied are you with the Service? Would you say that you are…

Very satisfied,	1
Satisfied,	2
Dissatisfied, or	3
Very dissatisfied?	4
REFUSED	-7
DON'T KNOW	-8

If QA4=1 (used LiveHelp), ask QD5. Else, go to QD7.

D5. Earlier you told me that you had accessed the cancer.gov LiveHelp service to have an online conversation about cancer or cancer resources. During your LiveHelp discussion(s), did you receive any links to web pages for cancer information?

YES	1	(GO TO QD6)
NO	2	(GO TO QD7)
REFUSED	-7	(GO TO QD7)
DON'T KNOW	-8	(GO TO QD7)

D6. How satisfied are you with the links you received? Would you say you are …

Very satisfied,	1
Satisfied,	2
Dissatisfied, or	3
Very dissatisfied?	4
DID NOT ACCESS LINKS	5
REFUSED	-7
DON'T KNOW	-8

D7. Following your contact(s), were you expecting to receive any materials by mail from the Service?

YES	1	(GO TO QD7OV)
NO	2	(GO TO QD10)
REFUSED	-7	(GO TO QD10)
DON'T KNOW	-8	(GO TO QD10)

D7OV. Have you received these materials?

YES	1	(GO TO QD8)
NO	2	(GO TO QD10)
REFUSED	-7	(GO TO QD10)
DON'T KNOW	-8	(GO TO QD10)

D8. Overall, how satisfied are you with the materials you received by mail? Would you say that you are…

Very satisfied,	1	(GO TO QD10)
Satisfied,	2	(GO TO QD10)
Dissatisfied, or	3	(GO TO QD9)
Very dissatisfied?	4	(GO TO QD9)
HAVE NOT READ MATERIALS	5	(GO TO QD10)
REFUSED	-7	(GO TO QD10)
DON'T KNOW	-8	(GO TO QD10)

D9. Why are you dissatisfied with the materials? (CODE ALL THAT APPLY.)

NOT RELATED TO REASON I HAD CALLED	1
DIFFICULT TO UNDERSTAND	2
DID NOT RECEIVE ALL MATERIALS REQUESTED	3
OTHER (SPECIFY) _____	91
REFUSED	-7
DON'T KNOW	-8

D10. Since you last contacted the Service, have you suggested that someone you know also contact the Service?

YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

D11. In the future, do you think you would recommend the Service to someone else?

YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

D12. In the future, if you have other questions, would you contact the Service again?

YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

D13. Before your contact(s) with the Service, how would you describe your knowledge about [(cancer)/(and) (the harmful effects of tobacco)]? Would you say you were…

Very knowledgeable,	1
Knowledgeable,	2
Somewhat knowledgeable, or	3
Not at all knowledgeable?	4
REFUSED	-7
DON'T KNOW	-8

D14. Do you feel that your contact(s) increased your (cancer knowledge)/[(knowledge about the harmful effects of tobacco)/(and cancer)]…

A lot,	1
Somewhat,	2
A little, or	3
Not at all?	4

REFUSED ..... -7
DON'T KNOW ..... -8

D15. How much of the information you received during your contact(s) with the Service was new to you? Would you say…

All or most of it, ... 1
Some of it,..... 2
A little of it, or..... 3
None of it? 4
REFUSED ..... -7
DON'T KNOW ..... -8

If QB1=1 and QC1A (QSMOKE) = 1 or QC1A (QUITTOB) = 1 (contact for self and contact about quitting smoking or quitting other form of tobacco), go to E1. Else, go to box after QE6.

TOBACCO USER RESPONDENTS ONLY

E1. Earlier you said that one of the reasons you contacted the Cancer Information Service at either the 1-800-4-CANCER number or the Quit Smoking Line at 1-877-44-U-QUIT was to get information about [ways to quit or cut back on smoking (and)/ways to quit or cut back on tobacco use such as chew, spit, or snuff]

If QC1A (QSMOKE) = 1 and QC1A (QUITTOB) = 1, read:
For these next questions, please think only about quitting or cutting back on smoking.

Which of the following best describes your decisions about (smoking/using tobacco)? Would you say that before you contacted the Service you had…

Already quit, ... 1 (GO TO QE5)
Already cut back,..... 2 (GO TO QE2)
Wanted to quit or cut back but hadn't done it yet, or..... 3 (GO TO QE2)
you had not yet made a decision? ..... 4 (GO TO QE2)
OTHER (SPECIFY)..... 91 (GO TO QE2)
REFUSED ..... -7 (GO TO QE2)
DON'T KNOW ..... -8 (GO TO QE2)

E2. I'd like to ask about any changes you might have made since your contact with the Service. Since your contact, have you…

Quit (smoking/using tobacco),..... 1 (GO TO QE5)
Cut back on (smoking/using tobacco), or..... 2 (GO TO QE3)
Are you planning to quit or cutback on (smoking/using tobacco)..... 3 (GO TO QE4)
HAS NOT MADE ANY CHANGE ..... 4 (GO TO QE3)
OTHER (SPECIFY)..... 91 (GO TO QE3)

REFUSED ..... -7 (GO TO QE6)
DON'T KNOW ..... -8 (GO TO QE6)

E3. Do you plan to quit (smoking/using tobacco)?

YES ..... 1 (GO TO QE4)
NO ..... 2 (GO TO QE6)
REFUSED ..... -7 (GO TO QE6)
DON'T KNOW ..... -8 (GO TO QE6)

E4. Have you set a date to quit (smoking/using tobacco)?

YES 1
NO 2
REFUSED ..... -7
DON'T KNOW ..... -8

E5. Did the suggestions from the Service help you (plan to) (quit/quit or cut back)?

YES 1
NO 2
REFUSED ..... -7
DON'T KNOW ..... -8

E6. Did the information you received from your contact with the Service change the way you think about (smoking/using tobacco)?

YES 1
NO 2
REFUSED ..... -7
DON'T KNOW ..... -8

If QC4=-1 (called for information about clinical trials), or if QC6=1 (received information about clinical trials), go to F1INTRO.
Else, if QB1=1 (calling for self), go to QF9. If Q6≠1 (calling for someone else), go to QF13A.

TREATMENT AND CLINICAL TRIAL RESPONDENTS ONLY

FINTRO. Earlier you said that you (contacted the Cancer Information Service to get information about clinical trials such as screening, prevention, treatment or other types of trials]/received information about clinical trials such as screening, prevention, treatment, or other types of trials, from the Cancer Information Service).

If QB=1 (contact for self) and QC4=1(called for information about clinical trials), go to QF2. Else, continue with QF1.

F1. Before you contacted the Cancer Information Service, were you aware that clinical trials were available as an option for some people?

YES	1	
NO	2	
REFUSED	-7	
DON'T KNOW	-8	

If QB1=1 (contact for self), continue with QF2. Else, go to QF13A.

F2. Has the information you received from the Cancer Information Service led you to seek more information about a clinical trial?

YES	1	(GO TO BOX)
NO	2	(GO TO QF5)
REFUSED	-7	(GO TO QF5)
DON'T KNOW	-8	(GO TO QF5)

F3. Have you found out whether or not you are eligible to participate in a clinical trial?

YES	1	(GO TO QF3OV)
NO	2	(GO TO QF4)
REFUSED	-7	(GO TO QF4)
DON'T KNOW	-8	(GO TO QF4)

F3OV. Were you eligible?

YES	1	(GO TO QF6)
NO	2	(GO TO QF9)
REFUSED	-7	(GO TO QF9)
DON'T KNOW	-8	(GO TO QF9)

F4. Do you plan to find out if you are eligible for a clinical trial?

YES	1	(GO TO QF9)

NO	2	(GO TO QF7)
REFUSED	-7	(GO TO QF7)
DON'T KNOW	-8	(GO TO QF7)

F5. What are the reasons you have not looked into clinical trials? [PROBE: Any other reasons?}

HAVEN'T HAD A CHANCE TO TALK WITH DOCTOR	1
DON'T WANT TO	2
DON'T WANT TO BE A GUINEA PIG	3
NOT SURE TRIAL IS AVAILABLE	4
POSSIBLE BAD SIDE EFFECTS	5
FINANCIAL STRAIN/CHILD CARE	6
INFORMATION TOO TECHNICAL	7
FAMILY NOT SUPPORTIVE	8
NO EVIDENCE I WOULD BENEFIT	9
DOCTORS MORE CONCERNED WITH SCIENCE THAN PATIENTS	10
NOT ELIGIBLE TO PARTICIPATE	11
HEALTH INSURANCE DOESN'T COVER COSTS	12
OTHER (SPECIFY) _____	91
REFUSED	-7
DON'T KNOW	-8

Go to QF9.

F6. Have you enrolled in a clinical trial?

YES	1	(GO TO QF9)
NO	2	(GO TO QF8)
OTHER (SPECIFY)_____	91	(GO TO QF9)
REFUSED	-7	(GO TO QF8)
DON'T KNOW	-8	(GO TO QF8)

F7. What are the reasons you do not plan to find out? [PROBE: Any other reasons?]

HAVEN'T HAD A CHANCE TO TALK WITH DOCTOR	1
DON'T WANT TO	2
DON'T WANT TO BE A GUINEA PIG	3
NOT SURE TRIAL IS AVAILABLE	4
POSSIBLE BAD SIDE EFFECTS	5
FINANCIAL STRAIN/CHILD CARE	6
INFORMATION TOO TECHNICAL	7
FAMILY NOT SUPPORTIVE	8
NO EVIDENCE I WOULD BENEFIT	9
DOCTORS MORE CONCERNED WITH SCIENCE THAN PATIENTS	10
NOT ELIGIBLE TO PARTICIPATE	11
HEALTH INSURANCE DOESN'T COVER COSTS	12
OTHER (SPECIFY) _____	91

REFUSED ..... -7
DON'T KNOW ..... -8

Go to QF9.

F8. What are the reasons you have not enrolled in a clinical trial? [PROBE: Any other reasons?]

HAVEN'T HAD A CHANCE TO TALK WITH DOCTOR 1
DON'T WANT TO 2
DON'T WANT TO BE A GUINEA PIG 3
NOT SURE TRIAL IS AVAILABLE 4
POSSIBLE BAD SIDE EFFECTS 5
FINANCIAL STRAIN/CHILD CARE 6
INFORMATION TOO TECHNICAL 7
FAMILY NOT SUPPORTIVE 8
NO EVIDENCE I WOULD BENEFIT 9
DOCTORS MORE CONCERNED WITH SCIENCE THAN PATIENTS 10
NOT ELIGIBLE TO PARTICIPATE 11
HEALTH INSURANCE DOESN'T COVER COSTS 12
OTHER (SPECIFY) _____ 91
REFUSED ..... -7
DON'T KNOW ..... -8

F9. Since your contact(s) with the Cancer Information Service, have you discussed any of the information you received with a doctor or other health professional?

YES ..... 1 (GO TO QF12)
NO ..... 2 (GO TO QF10)
REFUSED ..... -7 (GO TO QF10)
DON'T KNOW ..... -8 (GO TO QF10)

F10. Do you plan to discuss any of the information you received with a doctor or other health professional?

YES ..... 1 (GO TO QF13A)
NO ..... 2 (GO TO QF11)
REFUSED ..... -7 (GO TO QF13A)
DON'T KNOW ..... -8 (GO TO QF13A)

F11. What is the <u>main</u> reason you don't intend to discuss this information with a doctor or other health professional?

NEED MORE INFORMATION 1
INFORMATION CONTRADICTS/CHALLENGES WHAT THE DOCTOR TOLD ME 2
INFORMATION WAS NOT GOOD/NOT HELPFUL 3
DOCTOR IS TOO BUSY TO TALK ABOUT THIS/ DON'T WANT TO

BOTHER THE DOCTOR	4
NOT COMFORTABLE TALKING TO DOCTORS	5
CONFUSED ABOUT WHO TO DISCUSS INFORMATION WITH	6
OTHER (SPECIFY) _____	91
REFUSED	-7
DON'T KNOW	-8

Go to QF13A.

F12. How helpful was the information you received in terms of talking with a doctor or other health professional? Would you say it helped…

A lot,	1
Somewhat,	2
A little, or	3
Not at all?	4
REFUSED	-7
DON'T KNOW	-8

F13A. Please tell me if your experience with the Service has affected your confidence in your ability to seek information about (a cancer-related topic)/[(and) (tobacco)]? Would you say you feel…

More confident,	1
Less confident, or	2
About the same?	3
REFUSED	-7
DON'T KNOW	-8

If QB =1 (calling for self) and QB3 =1(has cancer), go to QF13C. If QB=1 (calling for self) and QB3=2, -7, or -8 (does not have cancer, or refused, or don't know), ask QF13B. Else, ask QF14.

F13B. Regarding your ability to understand the causes of cancer or potential risk factors for cancer, would you say your experience with the Service has made you feel…

More confident,	1
Less confident, or	2
About the same?	3
REFUSED	-7
DON'T KNOW	-8

F13C. Regarding your ability to actively participate in (your/your RELATION'S) treatment decisions, would you say your experience with the Service has made you feel…

More confident,	1
Less confident, or	2
About the same?	3
REFUSED	-7

DON'T KNOW ..... -8

Go to F14.

F14- Those are all the questions I have for you. Do you have any questions or comments?

YES, HAS COMMENTS, ... 1
NO, HAS NO COMMENTS 2

COMMENTS: _____

Your feedback on the Cancer Information Service will be very helpful and I would like to thank you very much for your time.

APPENDIX D: LETTER TO RESPONDENTS

October 14, 2003

Date

Dear Mr./Ms._____:

The National Cancer Institute (NCI) is evaluating its Cancer Information Service (CIS), a free public service of the NCI, the Nation's primary agency for cancer research. Recently, you contacted our service and at that time, you were asked to participate in an evaluation about your experience. This letter is in response to your request for additional information about the evaluation.

As part of the NCI mission to provide the most accurate cancer information to the public, NCI has contracted with Westat, an independent research firm in Rockville, Maryland, to conduct an evaluation with about 2,500 people who contacted the CIS. The public is able to contact the CIS either by telephone at 1-800-4-CANCER or online through *LiveHelp*, the CIS web-based service located on the National Cancer Institute's web site at www.cancer.gov. We will use the survey findings to inform and improve the CIS, and your experience with the CIS is important to that effort.

Our evaluation is strictly confidential, and results will be reported as a whole. We will not know how any individual responded to the questions. We want to assure you that neither your name nor your address will be disclosed to any individual or organization.

For the evaluation, Westat interviewers are talking with people from across the country. They are asking questions about users' experience with the CIS. For example, one question they are asking is "Overall, how satisfied are you with the Cancer Information Service?"

NCI is part of the U.S. Department of Health and Human Services and the National Institutes of Health. If you would like to learn more about the NCI, please visit our web site at www.cancer.gov. If you have any questions about your rights as a participant, please call Meredith Grady at Westat's toll-free number, 800-937-8281, ext. 2748. If you would like to talk with someone at NCI about the evaluation, please contact Madeline La Porta, Deputy Associate Director of the CIS, at 301-594-8025.

Sincerely,

Madeline La Porta,
Deputy Associate Director
Cancer Information Service
National Cancer Institute

Comment: I changed National Cancer Institute to NCI since the acronym is provided earlier in this sentence.

Comment: I added this so that recipients will link the CIS to the action that they took (i.e., calling or going online. I changed Cancer Information Service to CIS since the acronym is provided in the first sentence.

Comment: I changed Cancer Information Service to CIS since the acronym is provided in the first sentence.

Comment: I deleted the following sentence since confidentiality is assured in the first sentence of this paragraph. Repeated mentioning of confidentiality has been shown to raise suspicions rather than dispel them.

Comment: I changed National Cancer Institute to NCI since the acronym is provided earlier in the letter.

Comment: My understanding is that the regulations pertaining to research involving human subjects require that participants be provided the name (and contact information) of someone unaffiliated with the research from whom they can get information about their rights. In that regard, we cannot use your name here. Typically, the name that is used is someone from the IRB itself. Please let me know if you see a problem with this, and I'll discuss it with our IRB.

APPENDIX E: EVALUATION ADVISORY COMMITTEE

Sharon Davis
CIS Project Director
California

Alice Bradley
CIS Project Director
Rocky Mountain

Linda Fleisher
CIS Project Director
Atlantic

Rosemarie Slevin-Perocchia
CIS Project Director
New York

Shelly Peterson
CIS Research Associate
Heartland

Andrea Tapia
CIS Training Coordinator
Mid-South

Julie Kornfeld
Associate Director of Research
Coastal

Pamela Brown
CIS Principal Investigator
Mid-Atlantic

David S. Bushnell
Evaluator
Bowie State University

Marion Morra
CIS Consultant

Barry Portnoy
Office of the Director
National Institutes of Health

Vish Viswanath
National Cancer Institute
Division of Cancer Control and Population Sciences

Sabra Woolley
National Cancer Institute
Division of Cancer Control and Population Sciences

Kathryn E. Newcomer
Professor and Chair
Department of Public Administration
School of Business and Public Management
George Washington University

Teresa Lofton
Senior Study Director
Westat

William A. Stengle
CIS Project Director
Mid-West

Nancy McKeown-Conn
CIS Research Coordinator
Atlantic

Anita Redrick McFarlane
CIS Partnership Program Manager
New York

Dawn S. Sittauer
CIS Information Service Manager
Pacific

Sue Rutledge
CIS Training Coordinator
Pacific